

# COMMUNICATING TOGETHER

published by  
Sharing to Learn

AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 12, NO. 3/SEPT. 1995





NOLA MILLIN,  
SHIRLEY McNAUGHTON &  
PETER LINDSAY

*From Nola:*

Since we feel the themes of integration and inclusion are such important subjects in society, we are continuing to discuss them in this issue. We are looking at integration and inclusion and discussing quality of care and declining resources. Often people might think of integration and inclusion as being the same thing. As I read the articles for this issue, while having some health problems this summer, I began to realize integration and inclusion can be at the opposite ends of the spectrum.

Integration is always associated with getting people with disabilities out into the "normal" community whereas inclusion is thought of as making a person a part of a community or a group. To be *in* the community and to be *a part of* a community are two totally different things. In my mind, I differentiate between the two by thinking of integration as a physical act of being a part of a community, and inclusion as having to do with attitude. Our own attitudes help to determine how we handle the environment around us. I'm not saying attitude has everything to do with integration and inclusion, but it's a strong part of the process. As an individual with a disability, I have to know how to conduct myself appropriately in certain settings in order to be acceptable. When other people accept me, then I can be a meaningful part of the community and inclusion occurs.

I live in an apartment building in a subdivision in Windsor. Those of us who live in the building have

some sort of physical disability. The community has accepted us — sort of. The store owners and the local bank tellers all know us and are willing to accommodate to our needs. One would say that we are integrated into the community.

The problem lies in the fact that we are limited if we want to do any recreational activities except play bingo. I went through a period this summer when I felt very isolated. Friends were either busy or away on vacation. All of my committees were taking breaks. Even my church activities were cancelled until fall. Summer is usually a busy time for people, but for me, it was a very lonely period. Part of the problem is that adults who are physically disabled wheelchair users have limited opportunities to take part in recreational activities. We are integrated into the community up to a certain point. Then we are excluded. During my period of loneliness, I had some health problems. I knew my basic problem was that I wasn't getting with people enough, yet I was limited in what I could do. I had to readjust my own attitude and take the initiative to let friends know I needed them. Once I had things to do, and people to be with, I felt much better. Unfortunately, I have to rely on friends to do anything recreational.

Now, that I'm off my "soap box", let me review some of the articles in this issue. A lot of them are subtly saying what I have just said: Sometimes integration and inclusion are related and sometimes they are opposite to each other.

Our feature article is written by Judith Snow. Judith discusses the Latimer case, previously discussed in our December, 1994, editorial. In my

mind, this case exemplifies how exclusion, in its most severe form causes major distress in a person. Judith presents an interesting point. When Tracy is labelled as being severely disabled then people tend to have sympathy for Mr. Latimer. But when we think of Tracy as a twelve year old child, then people see Mr. Latimer as a cold-blooded killer. Presenting a different perspective, we have the transcript of a radio commentary written by Verna Thompson, a freelance journalist, following the sentencing of Robert Latimer.

Both Judith and Verna make valid points. Personally, I feel that society let the Latimers down. I think Mr. Latimer was wrong in taking Tracy's life; yet it's impossible to judge his attempts to get help for Tracy and her special condition. Was he a victim, himself, of declining resources, no resources at all or limited knowledge of what was available? I'm sure Tracy's family gave her the best quality of care possible, but they lived in a rural community where resources could be limited. Frustration can cause one to turn to alternative options. I know! When I was going through my period of loneliness, I felt limited by the lack of resources around me. Fortunately, I didn't allow myself to become suicidal. Though, I can understand how Mr. Latimer might begin to think that killing Tracy was the best solution. Read the articles by Judith and Verna and decide for yourself.

I'm pleased to have the article by Angel Joslin in *Yucks & Wows*. She shows how integration can be the opposite to inclusion. For Angel, being integrated into a regular high school system didn't mean she felt included. She felt more included



when she attended a segregated system. This was one of those times when integration proved to be a real yuck!

The *Teaching and Learning* section has two articles. I reviewed the book, *Communicating with Signs, Sounds and Symbols* by Claire Donovan. One of the opening statements Donovan makes is, "Without a functional communication system, community integration is very difficult, if not impossible." Donovan talks about AAC and how to implement it so individuals can have the ability to communicate. Suzanne Clancy's article deals with the program she is involved with at Mohawk College. It's a program where adults with disabilities can gain training in specific areas so that they can be integrated, and hopefully included, in the community. This sounds like a very good program for disabled adults who need preparation in order to manage the challenges of dealing with the pressures of the day-to-day world.

Kari continues her story of *Skallagrigg*. I don't know about you, but I'm finding this story quite intriguing. Besides being physical, inclusion can be emotional, or mental. I believe others can accept us, but we have to accept ourselves and our circumstances in order to feel included in society. I think Kari has found a way of accepting the events in her life, which helps with inclusion. Thanks, Kari. I can't wait for Part Three!

The theme of quality of care is apparent in the *Adapting* section. Brian shares how his life has improved by living in a hospital rather than living at home. One would think that living in a hospital would be more *exclusive*. But Brian points out that by being in the hospital, his needs are more easily met. Also, for Brian, being in the hospital has helped relieve the feeling of burden-

ing his wife. It is interesting to see how Brian feels he's learning the needs and wants of the staff as they learn his. Isn't this how inclusion takes place?

We have two *Perspectives* in this issue, one written by Max Korn and one written by Shirley McNaughton. Max draws our attention to the many ways in which we can devalue people with disabilities — more regarding Max's article from Peter and Shirley later in this editorial. Shirley shares some feelings and a very touching poem about her mother. The poem sends a tremendous message to everyone. It tells of the frustration of having to rely on others to meet our needs and invokes care providers to take the time to treat people respectfully. There are support staff in the building where I live. Unfortunately, there are times when I think staff forget that I'm a person. It isn't always their fault since sometimes they are so rushed that they haven't even had a break. Unfortunately, it's very demeaning when a staff member comes in with a "What do you want, now?" attitude. Shirley's poem reminds everyone that individuals are persons with feelings despite their sometimes intensive care needs.

In *Paul's Place*, Paul talks about how we all have struggles in life. It's a personal choice as to how we handle them. Paul's ideas are right on. Even though we might face changes in quality of care, or declining resources, we have a choice as to how we accept these circumstances. Part of integration and inclusion is our own attitude about the things around us.

Integration and inclusion are factors in the life of every person who has a disability. We can choose whether or not to become integrated and included into society, as much as society can choose to integrate and include us. I hope these articles and some of what I have said will help

the reader. I also hope the integration and inclusion process is as exciting for you as possible.

*From Shirley and Peter:*

We're directing our brief editorial comments to the articles by Robert Haaf and Geb Verburg, for both these associate editors seem to be adding a challenging new dimension to our integration/inclusion theme. Robert Haaf highlights the need to consider the individual being included in mainstream technology. Rob identifies many benefits for the AAC user who can move away from dedicated aids. We would emphasize the importance of mainstream computers having peripherals that allow the user access to mainstream software. All too often, the computer is equipped with additional capabilities that seriously complicate the addition of software that for the able-bodied individual requires a routine installation. We are encountering this problem often as we install BlissNet software on the mainstream/adapted computers of the consumers involved in the BlissNet Project.

In his usual fashion, Geb Verburg provokes some important thinking. His suggestion for gaining control over one's life is to "Live with the lowest rehabilitation and/or medical technology possible." We know many individuals who maintain their independence by doing just that! Yet technology can expand the AAC user's horizon dramatically. Maintaining a balance between one's own independent capabilities and the capabilities made possible through technology is certainly a challenge to be faced by every AAC user. We hope the AAC users among our readers find the articles by Robert Haaf and Geb Verburg helpful as they give thought to this matter. It's something each individual has to work out for himself or herself. We'd certainly like to hear from readers on this topic! §



## Responding to the Death of Tracy Latimer

JUDITH SNOW

*Judith Snow describes herself as a philosopher, lecturer and author. She is a self-employed consultant, trainer, and adult educator in the area of inclusion. As described by Judith, inclusion is a philosophy with its roots in the independent living, community living, normalization and human rights movements. Inclusion goes beyond integration, looking at the benefits and opportunities that accrue to all citizens when we encourage, nurture and support diversity in our communities.*

*Judith was born in Oshawa, Ontario in 1949. She has lived in Toronto since entering York University in 1968. After graduating in 1976 with an M.A. in Clinical and Counselling Psychology she lived in a chronic care institution for four years due to the lack of personal assistance supports in the community at that time. Her path out of the institution to a full, active and international life of participation is chronicled in **From Behind the Piano - the Story of Judith Snow's Unique Circle of Friends**, by Jack Pearpoint, Inclusion Press.*

*Judith Snow's work covers the areas of family support, personal assistance as a community living support, the development of support circles, and strategies for building inclusive classrooms. She also does strategic planning for inclusion with individuals and organizations. She works alone or with a variety of partners such as Jay Klein from the University of New Hampshire, Martha Leary, a speech and language pathologist, and Marsha Forest and Jack Pearpoint, also from the Centre for Integrated Education and Community. Her book, **What's Really Worth Doing and How To Do It - A Book for People Who Love Someone Labelled Disabled — (Possibly Yourself)** is also*

When I was seven months of age, I was diagnosed as having Spinal Muscular Atrophy, a form of Muscular Dystrophy. I was labeled 'severely physically disabled'. A cherished childhood memory is a conversation that I had with my father when I was about six. He explained that some U.S. doctors were putting children labeled 'mentally retarded' to death saying that society should not have to bear the burden of caring for these children. Dad, who grew up in rural England, explained that in his youth children with 'mental retardation' were able to grow potatoes along with everyone else. So they were a regular, accepted part of his community. But, in his boyhood, children like me were killed. People felt they did not have enough resources to support someone who would likely not be able to grow food.

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**Above all, together we must create a climate that teaches everyone that everyone is valuable and that everyone can contribute to our society.**

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As I passed through childhood, I met other children, some of whom did not speak. Now and then one of them would disappear - and we would hear that they had 'died'.

In November 1994, a controversy swept Canada. Robert Latimer was found guilty of murdering his twelve year old daughter by deliberately poisoning her with carbon monoxide. Although he freely explained his careful planning of her killing, he was found guilty only of second degree murder and given the minimum, ten year sentence. In the same year U.S. citizens called for the maximum sentence for a woman who drowned her two sons. But thousands of

Canadians raised over \$85,000 for Latimer to appeal his sentence. When his appeal failed unhappiness reigned. For example, the Canadian Civil Liberties Union published a statement calling for compassion for Latimer.

Are Canadians a nation of child haters? Not usually. The difference is that Tracy Latimer did not speak and needed extensive personal assistance. People called Tracy 'severely mentally retarded and physically disabled'.

We live in a era where every magazine, newspaper, radio talk show and TV station carries frequent stories about new achievements by 'disabled' citizens, new community programs and services, and the latest technological wonders. Yet apparently nearly everyone in Tracy's life and death - her family, all her medical consultants, the investigating police, the judge, the jury and many of the Canadian public - were ready to write off Tracy as a burden and as a person who could find no value in her own life.

I am an adult with an extensive disability. I know many others, now in our 40's, 50's, 60's, etc. How absurd it would be to judge our lives by our circumstances when we were 12. How absurd to be judged by others at all, especially by those who have never experienced a disability personally or who are unwillingly providing us with support or who don't listen to the voices we have.

If Tracy Latimer had lived into her 40's, 50's, etc., she would have suffered much - it is true- but she would have also found many caregivers, many friends and many ways to get her point across. She already enjoyed sharing her passion for music and for animals with anyone who spent time with her. Given time she would have offered many other gifts as well. And, with what we already know about supporting a person to live and work in the commu-



nity combined with what we will learn in the decades to come, no doubt Tracy would have been seen as a very important citizen.

How can we respond to this dangerous denial of human capacity, rights and worth? Recent history shows us that continued denial is dangerous for a whole society. In Germany of the 1930's, lawyers, doctors and university professors worked out ways of systematically killing children and adults labeled disabled. These methodical white-washing procedures made possible the holocaust of Jewish people and millions of others. Our present climate of killing people because they are a 'burden' or living a 'low quality' life can spread the death dealing again. We only have to keep on denying that labeling someone 'disabled' obstructs her or his human rights.

Our alternative is to see beyond the medical, technical and support issues and examine the human side of life. This requires courage - something not taught in professional text books. It requires a willingness to see people for who they really are - different perhaps in their minds and in their bodies, but not different in their spirits or in their willingness and ability to contribute to the mosaic of society.

The very act of labeling someone disabled is far more than a medical or support convenience - a way to get someone into the system. Labeling someone disabled is also a convenient way to justify unleashing all the powers that human hatred is capable of directing at someone. Labeling someone disabled leaves them an open target for ridicule, isolation, poverty, physical harm and murder. The statistics have always been there. Those who don't want to see them are merely kidding themselves at best.

The professional world must take an honest, hard look at the human consequences of labeling people. We must adopt other ways of appropriately supporting people to maintain their health and to contribute to society. These new methods must allow people who live with differently functioning minds and bodies to fully participate in their own care and in all of the decisions that affect their well-being and future. Above all, together we must create a climate that teaches everyone that everyone is valuable and that everyone can contribute to our society.

If we do not take this bold stand now, not only will there be more murders of other children like Tracy, but we will all suffer the consequences of a society that too easily hates and kills. We owe it to Tracy to turn this society around.

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## Commentary on the Death of Tracy Latimer

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VERNA THOMPSON

*This Commentary, initially presented July 19 on the Canadian Broadcasting Corporation, is re-produced with permission of the author and the CBC. Verna Thompson is a freelance journalist in Saskatchewan, the province where Tracy Latimer lived with her family.*

**T**racy Latimer is still not allowed to rest in peace. The 12-year-old's death in rural Saskatchewan focused national attention on the issue of euthanasia. Now her father, Robert, has had his conviction for the killing and the prison sentence upheld by the Court of Appeal.

The Latimer case is an emotional one. Those on Latimer's side see the sentence as far too harsh. They point to a loving caring father who could no longer see his daughter suffer. Many have rallied to his cause. Those who know him do not see Robert Latimer as an arch villain. On the other side are those who say that anything less than a ten-year sentence would be a travesty of justice. Whatever side of the issue one is on there are tough and disturbing questions.

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**As a society, we must ask ourselves, at what point do we draw the line. At what point did Robert Latimer cease to act in his daughter's best interest? Did he in fact ever cease to act in her best interest?**

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Our society professes to be a compassionate one. Had a dog or cat been suffering such pain as Tracy was, we would consider it an act of mercy to put it out of its misery. This raises the question, if it is compassionate to act that way for an animal, can we do less for a human who is in constant and severe pain?

For 12 years, it was accepted that Robert Latimer was a capable, responsible father, able to make decisions on behalf of his handicapped daughter, even to the extent of putting her through numerous painful operations. Any decisions Latimer made in Tracy's 12 years, could have been life and death ones for the child. Yet it is only on this final deed that society says he did not have a right to act on his daughter's behalf because he did not truly know how Tracy felt.



As a society, we must ask ourselves, at what point do we draw the line. At what point did Robert Latimer cease to act in his daughter's best interest? Did he in fact ever cease to act in her best interest?

We also must ask whether everything possible was done to alleviate Tracy's pain. As a family, did the Latimers explore all possibilities or did they just accept pain as part of Tracy's lot in life? And, one wonders, would the outcome have been different if the Latimers had lived in a city instead of rural Canada where medical services and support are

often far too hard to come by? At some point, the Supreme Court must grapple with the issues raised by the Latimer case.

The justices will also have to consider the sentence. Compared to those handed out to others who kill, is 10 years behind bars too harsh for a man who killed from compassion?

As individuals we too must deal with the issues and the outcomes. Had we walked in Robert Latimer's shoes, would we, could we have acted differently? If it is our verdict that in ending her pain the only way he could, Robert Latimer did not act

in his daughter's best interest, then we must determine where we draw the line. We must ensure that medical and support services are equal across the country, whether we live in rural Saskatchewan two hours from the nearest large hospital or, for example, in Thunder Bay, where care is minutes away.

Clearly, the Robert Latimer case is far from over. For the moment, it appears that Robert Latimer must pay the full price for Tracy's death. At the same time we must all confront the questions which have been raised and which as yet, go unanswered.

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## ISAAC

ISAAC (International Society for Augmentative and Alternative Communication) is a transdisciplinary organization devoted to the field of Augmentative and Alternative Communication (AAC). ISAAC has 2,300 members in more than 47 countries, including 11 national/regional Chapters. Membership is international and is open to all persons who are interested in AAC.

The purpose of ISAAC is:

- \* To advance the transdisciplinary field of AAC
- \* To facilitate information exchange
- \* To focus attention on work in the field

### ISAAC MEMBERSHIP INFORMATION

An ISAAC **Chapter** is a national, regional or language group of members who address ISAAC's mission at the local level by acting as advocates for the development of AAC within their nation or region. Activities of the Chapters include local conferences, newsletters and other publications in the local language(s), and involvement in national policy-making issues. ISAAC strongly encourages and promotes membership in its Chapters. **Chapter membership includes membership in ISAAC.** If you live in a country or region *where there is an ISAAC Chapter*, please contact the ISAAC Secretariat to receive further Chapter membership information and current membership rates.

If you live in a country or region *where there is not an ISAAC Chapter*, please contact the ISAAC Secretariat for current application form and membership rates.

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## Integration versus Segregation

NOLA MILLIN



Angel Joslin

The chart on the right hand side of this page contains Angel Joslin's responses to questions about her experiences with integrated and segregated school settings. Angel is now 22 years old. She has completed high school and is currently living in a Community Living Program.

I am really glad that Angel submitted this article to **Communicating Together**.

A special thanks goes to Mrs. Joslin who created the comparison chart. Angel is an AAC user and this chart shows how she feels about a segregated school setting in comparison to an integrated school setting.

Thanks, Angel, for your honesty. You remind us well that integration is not always the best option for everyone.

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### SOCIAL

### SEGREGATED INTEGRATED

*Sensitivity of Staff* X  
(Cried over this one re ability to read her needs)

*Peer Interaction*  
*Rapport* X  
(More comfortable with handicapped people)  
*Acceptance* X  
*Friendliness* X

(People laughed and talked with me)  
*Staring* X  
(Staring was much less)

*Talking down to* X X  
(Everyone talks to me like an adult)

*Isolation* X  
(Felt at home with peers and staff  
Never isolated from people or my surroundings)

### ENVIRONMENT

*Activities* X  
(Activities are geared to handicapped people)

*Subjects* X  
(Relevant subject matter)

*Accessibility* X X  
(Both about the same)

*Extra curricular activities* X  
(Activities and outings are modified for handicapped people at a segregated school; at an integrated school, I don't get to go out on field trips because my wheelchair is too much trouble)

### SELF ESTEEM

*Competence* X  
(More aware of surroundings; more confident of being independent)

*Importance* X  
(More responsibilities and independence. I ran errands for staff and felt important)

*Belonging* X  
(Don't feel left out. Everyone else has a disability like me)

*Rights* X  
(People being nice to me is all the rights I have. In a segregated school they give me choices and help me make correct decisions)



## A Book Review by Nola Millin

### Communicating with Signs, Sounds and Symbols

by Claire Donovan

Claire Donovan's book, *Communicating with Signs, Sounds and Symbols*, is a general book of 125 pages about Augmentative and Alternative Communication. In the preface, Donovan says "Publications about AAC are numerous, but most are in-depth textbooks directed towards professionals already working in the AAC field. This manual presents information clearly and succinctly and does not assume prior knowledge or experience." As a speech language pathologist, Claire writes this book using terms that are clearly defined. Technical jargon is used only sparingly.

The book is divided into five sections. The first section discusses what communication is and the methods that are used for communication. Claire then talks about how the process of communication develops normally in children. The second section outlines the cause of communication disabilities, feelings and reactions related to disabilities, and learning to accept a disability. Section three goes into the actual techniques of augmentative and alternative communication. Claire shows what AAC is and why one should use it. She tells about the "low" and "high" tech aids that make up the AAC repertoire. The fourth section discusses how to implement AAC. Numerous suggestions are

offered about creating, evaluating, and expanding AAC devices. The last section provides practical advice about how to teach people how to use the AAC devices, and strategies for developing communication.

Basically, I think the general public would find this book informative. It offers a good deal of insight into working with individuals who have various disabilities. Claire emphasizes the importance of keeping the AAC user as the centre of the team. I am also glad that Claire touches upon how support people are affected by AAC devices. If the device takes too much time, or training is required, then support people will be reluctant to let the person with a disability use the AAC aid.

Although I liked the general idea of the book, as an AAC user I had some concerns. My first concern was that the book tended to drag in places. I realize that Claire wants to convey a lot of information in the best possible manner, sometimes she presents too much information on a topic. I found that during these times I lost interest.

It is not clear who Claire thinks is her primary audience. I expect many readers with a general interest in AAC could lose interest because of the amount of detail that Claire's book goes into in some places.

Finally I was disappointed that Claire did not use quotations and comments from actual AAC users. After all, we are the ones with the most information since we are using these devices on a daily basis. I got the feeling that Claire was trying to tell people about AAC and how to deal with people who use an AAC device. The problem was that she did not allow any of us AAC users to communicate *our* thoughts about the subject.

Despite my criticism, Claire Donovan's book provides important information in a concise and simple-to-read manual. Professionals who need general knowledge about AAC for their work would benefit from reading this book.

Nola Millin

*Information regarding price and availability of **Communicating with Signs, Sounds and Symbols** can be obtained from the author and publisher:*

Clair Donovan  
7626 Mays Rd.  
RR#4 Duncan, BC V9L 3W8  
Canada



# TEACHING AND LEARNING

## Training Horizons for Adults in Transition: T.H.A.T.

SUZANNE CLANCY



*We are pleased to welcome Suzanne Clancy, a new Associate Editor, in her first 'solo' article in **Communicating Together**. We have valued Suzanne's input during the last two editorial meetings. In May, she accompanied another Associate Editor, Paul Marshall, on a trip to South Africa. For the past 15 years, Suzanne has been a teacher/life skills coach in a 40-week job readiness training program for mentally and physically handicapped adults at Mohawk College in Hamilton, Ontario. This is the program she describes in her first article. Her description of the program is timely given her focus on integration and segregation.*

**H**ello! It is a privilege to be invited to contribute to **Communicating Together**, and I am much honoured. I read Nancy Gibbons' article on segregation/inclusion in the June issue with great interest. I too struggled with the "S" word, albeit in a somewhat different format.

It is called Targeting Horizons for Adults in Transition. T.H.A.T. is jointly sponsored by Human Resources Development Canada (formerly called Canada Manpower) and by the Provincial Vocational Rehabilitation Services (VRS). Students attend classes every day in our own classroom on the main campus. We have a student/teacher ratio of 13:1. The academic component is self-paced with individualized program planning and one-to-one instruction. The life skills and job readiness training is taught through group process. The program was initiated in 1981 in response to community needs and I have been the principal instructor and coordinator since we began.

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**Graduates tell me over and over how good it is to have friends they can relate to and do things with, who will accept them for themselves and who are still there when the school term is over.**

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The academic curriculum includes numeracy, literacy, academic upgrading, and English. Job readiness training encompasses resume writing, interview skills, occupational health and safety, job search and maintenance skills and community work experience.

While all phases of the program are important, it is the life skills component that has the most direct impact on the future success of the students. Life skills as taught in the T.H.A.T. program, is defined as "problem solving behaviours appro-

priately and responsibly used in the management of personal affairs." Five major areas are covered: Self; Family; Leisure; Community and Job with emphasis on Self and Job. Topics include but are not limited to identifying personal strengths and weaknesses, effective problem solving, goal setting, decision making, values clarification, assertiveness training, and interpersonal communications. The aim is to develop a more balanced, self-determined person, with an enhanced sense of self-knowledge, self-worth and employability.

Graduates of T.H.A.T. achieve significant success in reaching their personal and job goals. Many have gone on to work in the community, some in competitive employment, others in sheltered settings with job coaching. Still others have gone on to further education and training. Periodic reviews of long term success rates have been positive and personally gratifying.

A major tenet of the T.H.A.T. program has been the belief that some special needs students learn best and are more successful in a more self-contained environment, with dedicated and trained teachers who have aptitude, ability and the time to focus on their unique needs. I believe that much of what I have been able to achieve with my students would be quite out of the question in an integrated college setting. Many of my colleagues have classes of 70, or 80, or more, students. In contrast to them, I have had the opportunity to get to know and interact with my students daily on a much more personal basis for 40 consecutive weeks. I have found this to be critical in helping my students reach their potential.



Although the T.H.A.T. program has been remarkably successful, Mohawk College has been under some pressure to discontinue this current model of teaching handicapped adults in a segregated setting and to fully integrate them in the Program of Study of their choice. It is suggested that the College would make any and all course and personal modifications and adaptations necessary, and provide ancillary services as needed. Such suggestions appear to be a result of the integration policies of local secondary boards of education. It reflects parents and students expecting that the colleges will (and can afford to) replicate the previous school experience. Need I mention the cost of such an endeavour, let alone the efficacy? The cost is enormous, and is a subject which needs a column unto itself, one which I hope to do soon. The effectiveness of such a decision, for the community, must be thoroughly and thoughtfully discussed by consumers, parents, teachers, advocates, employers, and anyone else interested in what "best meets the needs of the individual".

I am firmly of the belief that no one program or solution will most effectively meet the needs of all students with handicaps. A quick review of the articles in the June issue of **Communicating Together** will show that I am not alone in this position. Note also the response of Angela Joslin in the *Yuks & Wows* section of this issue. While some students do reasonably well in an integrated setting, others struggle and often lose confidence in their ability to learn and to gain acceptance as a member of the larger group. Over and over I have inter-

viewed and taught young adults who questioned why they were placed in an "integrated" classroom and graduated with a Grade 12 diploma only to discover, once out in the real world, that they were reading at a grade 4-5 level and had grade 3 math skills. They also expressed a deep sense of loneliness and loss as they watched many of their classmates go on to University, work, and marriage.

As Nancy Gibbons pointed out, it is the rare relationship between an individual with a handicap and one without that endures once outside the school setting. As for T.H.A.T., many graduates have developed deep bonds of friendship which have lasted 10 years or more. We even have the occasional wedding. Graduates tell me over and over how good it is to have friends they can relate to and do things with, who will accept them for themselves and who are still there when the school term is over. This degree of acceptance is not always as readily achieved in an integrated setting, especially in a College class with 50 or more students.

Lest anyone get the idea I'm a segregationist, let me assure you that at Mohawk we try to offer as inclusive an education as possible, while taking into consideration the students' needs, ability, and goals. T.H.A.T. students have access to most college resources including the library, gym, bookstore, student centre, health clinic and counseling. As programming throughout the college has expanded, more and more of my students are taking additional courses in upgrading, computers, liberal arts and business. Some are successful, others are not,

just as with any student. The difference is that T.H.A.T. students have the advantage of our support and our time to help them identify an appropriate course, organize their work and, perhaps most importantly, to boost their self-esteem. We give them encouragement to pick up the pieces when the world comes crashing down upon them. I am in the enviable position of having the time to help my students be successful. Many of my colleagues, while equally motivated, are not as fortunate and often lose otherwise good students for lack of time to help nurture the learning process, counsel and problem solve.

Inclusion for its own sake is not sufficient reason for placing a person in a situation which could well do much more harm than good. And as more than one parent has commented, it can be a form of abuse: psychological, physical and emotional. If it is finally decided that total integration is the only desirable route to take when educating the special needs individual, I would caution parents and advocates to simultaneously start planning the future social and employment needs of this target group. I can't imagine anything worse than all those raised expectations with little or no opportunity to exercise them. To me that would be the ultimate betrayal of trust — the final injustice!

## Reference

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## Mainstream Computers versus Dedicated Aids — Part Two

ROBERT HAAF

*This column is a continuation of the discussion begun last issue, where I stated my belief that the dedicated voice output device had perhaps reached something of an impasse in terms of its overall functionality, particularly in light of what is occurring with personal computer technology. I hope that anyone who read Part 1 has managed to reserve their opinion of my arguments and conclusions until now. This time, I plan to continue expressing my thoughts on voice output devices, and suggest some possible alternatives that I hope will challenge professionals, AAC users and device manufacturers alike.*

When we look at the development of dedicated voice output devices over the eight years that I've been in the AAC field, we move from, for example, the bulky Express III with its poor synthetic speech output and virtual unmountability, to the Liberator™, with its increased portability, wide range of access methods, icon prediction, DecTalk speech, etc. In the same time period, we have seen the development of devices with dynamic displays, which have provided a much-needed alternative to the stacks of paper displays that plagued our clients' existence for years.

When we look at such changes in isolation, I think it is perfectly understandable that we have viewed them positively. We have come a long way. What we tend to ignore,

however, is that in the larger perspective of technology development, these changes in dedicated devices, which at first may seem dramatic, can't possibly measure up. When compared to computer systems that are widely available (not to mention much cheaper), the capabilities of even the most sophisticated voice output devices can seem primitive, and almost impossibly limited.

I certainly do not mean to suggest here that there weren't some very real and compelling reasons for originally choosing the dedicated aid path. The development of dedicated devices came about as a result of a very real dilemma that existed until quite recently. Computers were at first not at all portable, and when they became so the first models were bulky and prone to crashing at every opportunity. However, the ongoing development of dedicated aids has largely ignored the fact that the development of laptop computer technology has proceeded at a blistering pace, a pace with which manufacturers of dedicated aids cannot hope to keep up. Instead, what many continue to do is work to transplant small pieces of the computer into their machines to provide some semblance of the computer functionality. Is there any compelling reason why this trend should continue?

I will try to anticipate at least one possible argument at this point: Some manufacturers of dedicated aids have maintained that laptop computer systems are more prone to breakdown than are their devices. From a personal standpoint, where I set up and maintain both dedicated and computer-based systems, I have little evidence to support this. I see crashed voice output devices at about the same rate as I do computer systems (keeping in mind the relative proportions of each in use by our clients). Also remember that the

developers of standard laptop computers continue to be very motivated to produce crash-proof systems for every computer consumer, and the development of such systems has been moving just as fast as the development of lighter, more compact laptops, high resolution colour screens, longer-lived batteries, portable CD-ROMs and all of the other innovations that you can probably recite as well as I.

I have worked with dedicated voice output devices for a number of years, and have what I feel is very good knowledge of their capabilities and limitations. Additionally, I have worked with a variety of computer systems including everything from word processing to software development. Given this background, I can state the following without reservation: From the standpoint of aided communication, there is *nothing* that a dedicated voice output device can do that a computer could not do, given the right software. More importantly, the features available on any of the voice output devices could be extended and improved upon in significant ways, providing users and care providers with much-needed functionality in communication as well as integration with many other computer functions.

As a hypothetical example, let's consider an individual using a Minspeak™ device, the Liberator™, with Interaction, Education & Play (IEP+), a Minspeak Application Program that provides a variety of theme-based vocabulary centred around social interaction, school themes, stories, jokes, etc. Our hypothetical Minspeak™ user is an indirect accessor, using a two-switch step scanning strategy quite efficiently. She has used IEP+ for some time and is familiar with all of the pre-stored vocabulary, as well as all of the customized vocabulary that family and



teachers have stored for her. The Liberator™ is positioned on the front of her wheelchair, and she can use it for communication in a variety of environments. When she needs access to a computer for writing, she is hooked up using an additional cable and access software. Various functions for operating the computer (mouse control, etc.) are stored into her Liberator™ to allow her to control the computer software more independently. To many readers, this is almost certainly a highly familiar situation.

Now compare this scenario to the following: The same individual has a colour Macintosh Powerbook computer mounted on her wheelchair. The IEP+ keyboard overlay (in full colour) appears on screen when the computer starts up, and via a small switch port in the back of the Powerbook the user can immediately start scanning the display. The user can choose to access IEP+ in full communication mode (where all 128 locations are available); messages generated in IEP+ could be spoken via an external DECTalk unit, or through one of the highly intelligible voices provided with the Macintosh system software. The user, who is able to independently move between a number of software applications, could also choose to have a smaller floating window that would pop up on screen when she is using her other software. This window would have a sub-set of the IEP+ icons (selected by the user) with a number of much-needed messages and the ability to quickly bring up the full IEP+ window. In fact, the user could have several different pop-up icon windows, which in addition to spoken messages could each have control commands customized for the needs of the program she is using (one window with letters, punctuation and a word prediction module for word processing; one with mouse commands and macros for drawing programs, etc.)

Now, let's imagine that our IEP+ user is going to be making the transition to Words Strategy™ (another Minspeak™ application program) to accommodate her growing vocabulary and grammatical skills. Words Strategy™ offers a greater degree of linguistic sophistication in a similar interface, but unfortunately does not share many icons, vocabulary or common icon sequences with IEP+. (At the 1994 ISAAC Conference, McGann, Kovach & Tullman outlined this process in detail.)

In the first, traditional scenario, the Liberator™ paper overlay would have to be transformed, hopefully in a gradual fashion, by having someone change icons, the icon positions and the sequences under which vocabulary items are stored. To make room for new icons, existing icons would need to be combined as well as moved, with the stored vocabulary changing as a result. Before and after every step, the changes would need to be reviewed with the user, with new icons being introduced in training activities designed to highlight the new icon associations. This is obviously a long term project, with the promise of significant effort expended on the part of the user and all of her caregivers

In our computer-based scenario, individual icons could be combined and/or replaced simply through a few software commands. The changes could be as gradual as necessary, without ever requiring any transitional overlays to be constructed. As new icons are introduced, a training mode would be available, so that as the user explores the overlay and selects new icons, instead of just speaking a message the icon could enlarge, speak and animate to demonstrate and help teach various icon association strategies. Additionally, the user could access a wide variety of Minspeak™ and Words Strategy™ teaching materials directly on the Macintosh, materials incorporating audio, video

and animation to train all of the basic concepts. These could include, for example, story books that allow the use of specific icons to navigate through stories that highlight Words Strategy™ associations. The user's therapists and care providers could have access to guides and training materials for suggestions on implementing Minspeak™ use in functional settings. Since all of these materials would be available on disk, the user and caregivers would be able to access them independently by exploring each new overlay. Finally, Words Strategy™ and all of the materials needed (in fact all of the existing Minspeak™ Application Programs), the training materials and tutorials proposed, the storybooks, *everything* I have described could be stored and distributed on one 5-inch CD-ROM, probably with room to spare. When it was time to move to another application, a user or her family could simply call the company to receive a password that would unlock an entire set of software, manuals, tutorials, etc., from the CD.

Sound interesting? OK; here's the punch line: All of this can be done not in some virtual reality daydream scenario, but on computer systems available now. The software I've discussed above could be created for the Macintosh starting today, and would not even require a developer to know much about programming to do so. You may only have my word on this, but the sheer power and capacity of existing computer systems make this not only possible, but relatively simple. The only reason that this system is not available is that to date it has not been the focus of developers.

To be sure, some developers of AAC devices have in fact been focusing on developing applications for existing computer platforms. On-screen keyboards are available that offer pop-up windows in any compatible program; software applications are



available that allow the creation of overlays on laptop computers, even incorporating colour photos, sound and video into the traditional symbol displays. Of course, my argument is not specifically with these products; I think they represent a positive step in the direction I'm advocating. I must point out, however, that each of these products continues to have significant limitations in the way in which they exploit the power of the personal computer for the user's benefit. Not one of them thus far has begun to approach the level of functionality and integration I've described above. For example, the on-screen keyboards available are designed primarily for literate, non-symbol users, and are not as easily customizable as they need to be. The software applications that allow the creation of symbol displays are separate programs that to date make no attempt to integrate with other applications on the computer (which begs the question: why put them on a computer platform at all?).

At a developer's conference I mentioned last issue, I approached a representative of one of the companies making symbol-display software and asked him why a greater degree of integration between the communication application and other software was not pursued. I outlined the idea of a pop-up symbol window, and his response was puzzlement. Why would someone who did not spell want or need to have such a window available? I'm afraid that I didn't understand his response then and still don't.

For *all* of the developers of existing computer-based AAC products, I have another question. Why can't the potential of the computer be better utilized to accommodate a user's skills and knowledge, by providing a more natural interface for communication and training purposes? Instead of a McDonald's page with a flat, two-dimensional picture array, why not a three-dimensional representation of

the McDonald's counter and pictorial menu, with a training module that utilizes video and sound, "Welcome to McDonald's. May I take your order?" Instead of (as in one application) moving between a series of text boxes to assemble stories for communication, why not be able to click on realistic picture icons representing home, school, the mall, etc., within a three-dimensional community map? This is *all* possible *now*, and by the time AAC applications catch up to present-day technology, the technology will have transformed again. Is there any hope we in AAC can actually catch up?

Last issue, I mentioned that there were actually three influences that act to separate AAC users from current technology. Yet I have spent two issues talking about only two of these — technology transfer and dedicated aids. The third is a funding issue: in our time of restraint, diminishing resources and making do with less, the idea of providing clients with state of the art technology is viewed with increasing suspicion and alarm.

After some reflection, I think that I can deal with this third issue very briefly, because from the standpoint of appropriate technology the issue is really a non-issue. Funding agencies would actually stand to benefit in several ways from the technological shift I've been discussing. Computer-based systems are cheaper, and, because of economies of scale and widespread consumer demand, will always be cheaper than dedicated AAC devices. Additionally, fiscal limitations have led to increased discussions of equipment recyclability, where older or unused aids can meet the needs of other clients and therefore reduce expenditures. Compare a device that only allows a user to store and retrieve spoken messages with a device that can meet face-to-face communication needs, written needs or any combination of both, that can

grow with the abilities and needs of a user without requiring continual hardware modifications, and that can be changed from multiple-page communication displays to a Minspeak-based display simply by changing software. Which communication aid is more recyclable?

Aside from this, there may still be those who maintain that disabled individuals do not need access to state-of-the-art computer technology, or at least should not be able to access public funds for anything but the most *basic* system. These people must answer a simple question: What is it that we do with this technology that a disabled person can't or shouldn't be permitted to do?

In discussing this article with colleagues, someone pointed out that the debate between dedicated vs. computer-based AAC systems is hardly a new one in our field. While I agree, I feel it necessary to point out that the stakes are different now for AAC users. What has changed, I think, is that the personal computer has transformed itself over just the past few years. While previously the argument between dedicated and integrated was one of balancing pros and cons for individual clients, it is becoming increasingly difficult to think of any compelling argument that favours the continued development of dedicated aids. At one point earlier I stated that there is nothing that a dedicated voice output device can do that a computer could not do, given the right software. My final word to AAC developers, then, is this: Give us the right software. Your consumers, *all* of them, deserve no less.

§

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# KARI'S SKALLAGRIGG

KARI HARRINGTON

*Kari continues to share her excitement over discovering her own Skallagrigg in this, the second episode of her most recent writing.*

## Four years ago

Oh man, if only I had had this strong feeling about Skallagrigg four years ago when I had my brain surgery which is my biggest life crisis so far. In 1991, I had my usual eye check-up. The ophthalmologist took forever to examine my eyes and he kept looking back to my charts. My left eye wasn't responding to the light very well. This had been recorded in my charts over seven years ago, but never was mentioned to us, figuring that it was a part of my cerebral palsy. The ophthalmologist didn't want to alarm us, but he told us that we should go and get a C.A.T. scan done. When the doctor got the results back, even he was surprised to see what we saw on the C.A.T. scan. A cyst had grown in my brain pushing it to one side. The doctor said that I didn't have cerebral palsy and that I had a brain defect. He said I should have an operation to get a shunt put in to drain the fluid in my brain. He also said I would probably get more body function and it might stop the seizures. As we were walking back to Participation House I became upset and scared. Not so much about the operation itself, but about what he said, about not having cerebral palsy. All of my 26 years I thought I had cerebral palsy. Now they were telling me that I didn't. What does a brain defect mean anyway? When the doctor said that I would get better body function, I thought it meant I would be walking and talking. I sometimes wished I could walk, especially be able to talk, but it would still be scary to wake up

and be a whole different person. I felt I lost my identity.

It took me two days to settle down. We decided I still had cerebral palsy, but the cause of it was different. I had the operation. There is not much difference in my abilities and it left me with a whole new bunch of medical problems - headaches, bladder infections, more seizures, and trembling and biting lips, but I didn't have a choice about the operation. It had to be done. I can't stop wondering what if I had believed in Skallagrigg back then. I believe I wouldn't have suffered mentally, and maybe physically as much as I did.

## Two Special Friends

The closest I got to Skallagrigg during those times was Sharon Smith, an aide who works here at Participation House. Her son had the same operation so she knew what I was going through. It got to the point where I wanted her all the time. I hardly made it through on her days off. As two years passed, I started to let go of her as I was recovering mentally. Once in a blue moon I will still need Sharon badly. Here is the poem I wrote for her.

You are the one  
Who knows what I go through.  
The pain I have  
Physically and mentally.

You are the one  
Who listens and talks  
About my problems and my joys.  
I can share everything with you.

You are the one  
Who I can count on  
To make me feel better,  
Even when you're not there.

Everyone needs a close friend.  
I'm lucky to have found mine.  
I want to thank God  
That you are the one.

Then there is Kathy Pahl, a recreation and activation staff member. She attends to my physical problems. I was slowly losing my walking abilities (I used to be able to walk along with someone holding me from behind. My parents were about only the ones who really could do it properly.) Because of this and with my hip and back pain, Kathy started to do physio with me on a raised mat. The physiotherapist had given suggestions for exercises that might be tried. My program had two stages. First I stretched out on my stomach and Kathy put the heating pad on my hip or back. Then I rolled onto my back to do arm and leg exercises. As my hip got more painful, we stopped the leg exercises.

Although I usually blank out and get all floppy after I get back in my chair, the exercises do some good sometimes. I also go in the pool every other day. Sometimes I check if Kathy is in the pool when I am. The other recreation staff are good, but Kathy is absolutely the best. Now with the new recreation and activation program, Kathy gets busy, so when I do ask her if she could get me out of my chair I don't get my hopes up. The best we can do, if it isn't possible to get out of my chair, is to shift my hips around and if I feel I need it, to plug the heating pad in. I think I feel attached to Kathy as much as I was to Sharon four years ago. In time I will let go a bit. Already I have found a group of people who can shift my hips in the special way I need.

*To be continued next issue ...*

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## Communicating Togetherness or To the Far Side?

MAX KORN

*We welcome Max Korn to **Communicating Together** as he questions why professionals still devalue people with disabilities! In addition to his responsibilities as Senior Consultant, Communication Aids, Assistive Devices Program, Government of Ontario, Max gives presentations relating to rehabilitation and normalization and, as well, does stand-up comedy. His humour rests on the tip of a very substantive iceberg! We were unable to print his entire paper and reference list, but we would be pleased to send a copy of his full article upon request.*

Don't you think you're making a big thing about the 'name and acronym' thing?" the speech pathologist asked me after my talk at the annual conference of the Canadian Rehabilitation Conference for the (sic) Disabled (Korn, 1994). Her view wasn't shared by the fellow who wheeled up to tell me that he shared my feelings, but had not confronted professionals because he might be wrong. "Well," I asked him, "how would you like reading this announcement if you didn't know what the acronyms stood for?"

**"The PIG will provide the PIS handouts of the CRAP and BARF."**  
(All these names are real!)

My conviction that I was not making too much of the acronym issue was soon reaffirmed. While visiting this speech pathologist's world famous rehabili-

tation facility, I read in its newsletter about the new FART program (Family Advocacy Resource Team). I pointed this out to the above speech pathologist and an administrator; I suspect I wasn't the first critic. However, I take no credit for the program now being referred to as the FARS [as in farce] (Family Advocacy Resource Service). The name is OK, but its use as an acronym, with less-than-image-enhancing qualities, underscores the primacy of the ideological issues facing us.

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**"The PIG will provide the PIS handouts of the CRAP and BARF."**

**PIG** = Parent Information Group  
**PIS** = Parent Information Service  
**CRAP** = Community Residential Alternatives Program  
**BARF** = Boston Association of Rehabilitation Facilities

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Consciousness of acronym-image issues obviously was in the minds of the Maritimers who decided to throw out the following choice of names for a new college: the "Samuel Holland Institute of Technology". There exist many examples of names and acronyms that are both positive, e.g., Adult Basic Living Experience (ABLE), People Learning Useful Skills (PLUS), Vocational Independence Program (VIP). The issue of acronyms is only the tip of this values-based iceberg. This tip reflects a large mass of heretofore undisclosed unconsciousness in human service workers' attitudes towards people with disabilities, how they refer to persons with disabilities, where they locate services, how services are structured and delivered, etc.

How can we people who work with persons with disabilities be so devaluing? In this era focusing on political correctness and fiscal restraint, why are we not bringing value to our work with raised consciousness: something that may be accomplished with little effort and cost? Can you understand the frustration of my friend, a consumer — after getting the president of a rehabilitation centre to understand why the staff made him feel so devalued, my friend learned that the staff training director didn't think the staff needed this "sensitivity-type training," because the staff "after all, had been working with persons with disabilities for many years."

But sometimes, the professionals and advocates you most expect to be conscious of issues regarding persons with disabilities promote harmful initiatives. Even our recent human services history reads like tales from the halls of infamy. For example, there was the UPI press report about the United Cerebral Palsy Association offering "to use their clients" to help clean up the Love Canal toxic waste dump sites in the Niagara Falls area; similarly, scientists proposed sending 'SWAT Teams' of old people in to clean up nuclear power station accidents, "because supposedly, they would die anyway before they would get cancer from radiation" (TIPS, 1981, p. 7). We see TV programs extolling the virtues of volunteer programs that bus children with disabilities into prisons for 1:1 relationships with felons (would you let your own child be transported for this volunteer program?). I remember reading about the three teenagers who, after being charged for killing a man with



a mental handicap, were sentenced to perform community service at the sheltered workshop where the victim had been employed — the director of the agency refused to accommodate these murderers working alongside the victim's former peers. Unfortunately, the director of the agency in the neighbouring town welcomed the free labor for her workshop. Enough!

### **Need to Internalize the Principle of Normalization**

The principle of normalization serves as a cornerstone for planning, developing and evaluating human services. The 25th anniversary of the first systematic statement of the normalization principle (Nirje, 1969) was marked in 1994 with an International Conference in Ottawa. Attended by over 400 people, the proceedings covered a wide range of issues (Flynn, in press). However, normalization per se has not been written about systematically in the area of augmentative communication. So it's no wonder that our unconsciousness in our work, like the above acronym examples, has a negative impact on public attitudes towards people with disabilities, and on persons with disabilities themselves. What messages are we giving the public with the above four examples of program associations with toxic waste and criminals? We advocates are constantly complaining about public attitudes, but we have got to clean up our acts first if we expect to change public attitudes.

### **So What is Normalization, Where Did It Come From & Why Is it Such A Big Deal?**

About 30 years ago, before the term inclusion had been coined, there was a void. This consumer's view gives a glimpse of life in the institution that many are familiar with:

I've always suffered from Dickens' Syndrome. This is the fear of being put in a large institution and having to stay there for the rest of your life. Your every move is controlled by the people who run the place. You are told when to wake up and when to go to bed. As far as food goes, of course they feed you, but you have little to say over what you want to eat. Leisure time? There's plenty of it, but there's nothing to do. A few old books are over there on a shelf in a corner, but you've read them all and new ones won't be arriving any time soon. The television's always turned on but never turned to something you want to watch. It's like this, year after year—nothing to do—forever.

(Williams, p.2, 1994)

This fate is a reality still for many people today worldwide. In 1969, Bengt Nirje described the Danish and Swedish experiences while introducing normalization as a principle that “underlies demands for standards, facilities, and programs ...” (for persons with disabilities): normalization means “making available to (persons with disabilities) patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (p. 181).

In a seminal monograph leading to the systematic de-institutionalization of residential services, Dybwad (1969) outlined four interrelated corollaries of normalization: integration, dispersal, specialization and continuity. Integration referred to both physical and social integration, and is a basis of the dispersal corollary, i.e., to distribute the location of smaller services more widely among populations. specialization means to separate children's from adult services, separate living/work/education/therapy and play environments from one another, etc. The above four corollaries

were expanded with “the developmental model” corollary, e.g., every person, no matter how disabled is a dynamic being capable of growth which may be enhanced through suitable environmental prostheses & opportunities.

Measurement of program quality and outcomes is a hot topic today. While the great importance of normalization is widely acknowledged, many who agree with the principle wholeheartedly, engage in practices quite opposed to it (Korn, 1987). A study of 256 community and institutional services concludes that the typical human service agency performs at less than the minimally acceptable level of normalization measures (Flynn, 1980).

I have vivid memories of visiting adults lying in cribs, muscles atrophying, with no means of communication, in clean facilities that received favourable accreditations every few years. The above quote by Michael Williams regarding the “Dickens Syndrome” speaks about large institutions. But size is not the only determinant of an institution. Wouldn't a supported living environment for one person, perhaps even in one's own home, also be an institution if the resident's life was excessively controlled by another person?

### **Time for Re-Evaluation**

Professionals are investing heavily in quality management and outcome measurement training and initiatives that pay little mind to normalization issues. Instead of asking “how well are we doing things?”, we should be asking “are we doing the right thing in the first place?”. Or, “to what extent do we have the right personnel doing the right things the right way with consumers, in the right place and time?” Otherwise, we may merely be congratulating ourselves for successfully devaluing people (albeit subconsciously).



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## Till She's Free

SHIRLEY McNAUGHTON

With the expansion of **Communicating Together's** mandate to share life experiences relating to persons with acquired speech impairments as well as those with congenital impairments, this poem, written by me during the early seventies, seems very relevant. My mother suffered a severe stroke in November, 1971 and lived until April, 1978 with very limited physical and communication capabilities. Her suffering and mine were intense. This poem was framed and hung at the head of her bed in the nursing home in which she lived for six long years. Writing it helped me to express the helplessness I was feeling at being unable to reduce Mother's anguish. Perhaps, the reading of it helped sensitize some of the doctors, nurses and aides who entered Mother's life during this time. I know that my quiet and respectful manner calmed her and we had many peaceful times together. I also witnessed many angry and tearful outbursts when care-givers patronized her, forced her to comply or ignored her attempts to gesture and talk. She was unable to learn to use even the simplest picture board due to her cognitive damage and the inconsistent use of the board by her care-givers. She never stopped attempting, however, to express her wishes through her body language. We developed our special way of communicating during our times together, but it was impossible to transfer the techniques we used to the constantly changing staff. Hopefully, this poem can be used to-day by **Communicating Together** readers who are striving to bring compassion into the lives of those who are "waiting to be free"!

### TILL SHE'S FREE

They called it a stroke,  
Hitting hard and strong,  
Life — as she knew it — stopped.  
*When Will She Be Free?*

She stays alive,  
A stranger to life,  
Suffering anguish, confusion, pain.  
*Share Her Vigil Till She's Free*

Unable to speak,  
Yet longing to confide  
Inner torment, questions, desires.  
*Understand Her Till She's Free.*

Her right limbs are locked  
Into rigid stiff place;  
To be moved  
Means intense lingering pain.  
*Be Gentle Till She's Free.*

Kind, sensitive care,  
With calm, quiet talk,  
Her needs can be met with Love.  
*Please, Help Her Till She's Free.*

Her wait has been long;  
Empty days stretch to years;  
Time, marked only  
By thoughtful acts.  
*Till Death Makes Her Free.*



## Quality of Care in a Chronic Care Hospital

BRIAN PAMPLIN



*Brian Pamplin, with friend and co-editor, Alda Steprans.*

**T**he quality of care that I get in the hospital is better than what I got at home. I felt good while the nursing assistant, who came to care for me in my home was there. But when she left, around noon, I was on my own for the rest of the day. I discovered I was no nurse. I couldn't leave the burden on my wife, Bernice, to look after me. She never thought of me as a burden, but I felt that I was. There were a few times that Bernice had to rely on her mother, who had been a nurse, to help me with my problems. There was no one else I could think of to help. In the hospital there is always someone there.

One time I had a problem catheterizing myself and started to bleed. It scared Bernice very, very much. Her mother got to help us again.

When I think back on it, it probably scared me to a certain degree as well. I thought I had done something bad to myself. The only reason I was not more scared was because it didn't hurt.

Having help nearby helps me feel much more secure. I have a unique talent of getting sick extremely quickly and seriously. It scares me. When I become sick, everything becomes a challenge. Breathing and eating become difficult to do. Having someone around helps me cope.

One time I came back from Variety Village and when the nurse brought my dinner tray to me I just said to her that I did not feel well, and that I wanted to go to bed. Right then she took over, wheeled me to my room and put me to bed. She knew something was happening. She knew that something was different even when I, myself, did not know how sick I was going to be. It would have scared the heck out of me if I had known.

I find that the agency nursing is a necessary evil in the hospital. Without agency staff, we would have nobody to care for us when there are not enough regular staff members on duty. However I find that the agency staff members don't always know what is best for me. They know they don't know what I like and dislike. Agency nurses who come often become like staff nurses because they get to know us and try to do things the way we like. I find that they do make an effort to comply with my wishes but given my speech problem, it is hard to communicate with them. It frustrates me when I cannot tell them what I like.

As far as regular staff go, they are still learning my needs and wants. It is a learning process for me as much as it is for them. I am also learning their needs and wants. I think it helps if we try not to put excessive demands on them. Sometimes I think I do that. I don't want to become like some of the other residents who make unreasonable requests. Some residents ask for things they could do for themselves. Others ask a number of staff to do the same thing for them. I find I am more tolerant with the regular staff learning my needs because I will be dealing with them again. I feel that I get good quality care in the hospital I live in, but I know that's not available everywhere.

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### Rising Above

PAUL MARSHALL

**I**t was the night before I started my column and all through the house, all was quiet, not even a computer was going. As I lay in my bed, thinking about an article, I realized that my deadline was five days away. When I went through my mind-filing system trying to come up with a theme for this column, I came up with this file named "wounded". We get wounded many times on this hilly road of life. We get hurt by events and by people.

As we talk about the forever ongoing battle of being integrated in the mainstream of our society as handicapped members, the words wounded, healed, growing and developing to be a healthy individual must be addressed. In my own life, I know that I am forever changing and developing. I can learn from my wounds or I can just bandage them up so they will never heal as a healthy part of my being. As we address "How to provide quality care?" "The decline of resources." "The technology lag", it is important to view these issues in this light.

We love to point our fingers and say if only I have these things or those people in my life then I would be a better person. We love to look at that greener field just across the road and say — if only. The more I go through experiences, the more I realize it is not the things that we have in life, it is all about how we react to circumstances that we can't control or change. I know all too well, I will always struggle in this area. We might wish we would reach that great stage in our lives where we

have it all together, but we will never reach that level. Life is ongoing learning, developing, reaching and growing. I hope I will still be undergoing changes and growing until the day that I die.

When it comes to providing personal care, it is vital we as consumers of the care and as care givers realize we are undergoing this study of learning, developing and growing. We need to realize any of our relationships take a great deal of work. When it comes to personal caregiving, it is that much harder on each party. I am personally greatly blessed because I don't need a lot of personal care. But I am somewhat aware of some of the trials and difficulties when it comes to getting help with daily needs.

When it comes to declining resources, this too is a very real part of living in a world that is changing each time that we turn around. We often think and look to our government to provide the big answers. I believe we as members of our society have the responsibility to advocate for people with all kinds of handicaps. To me there is a very fine line

between advocating for the right to be able to take part fully in society and advocating just because we think we should have it coming. We are the voices of countless individuals who can't speak for themselves.

Let me leave you with some other thoughts. Life is about relating to the world and people around us. It is our outlook on our own life that makes or breaks life. We are given a choice. We can accept and adapt to our environment, or we can stop being willing to accept and adapt. We have the option to live upright and grow from mistakes or we can stop learning on the road of life. If we stop developing, that is when we stop being healthy individuals in the community. We don't have the right to take a life and tag it with a 'stop learning' sign. We must see life as a great gift to enjoy.

As in each of my columns I hope this one will move you on with new views and thoughts. As always I am open to your comments. Please write me in care of **Communicating Together** or send an E-mail message to:

Paul.Marshall @ ghbbs.com

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## COMMUNICATION OUTLOOK

### FOCUSING ON COMMUNICATION AIDS & TECHNIQUES

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## Labelling = Murders?

GEB VERBURG



As is so often the case at the start of writing a column I have many things to tell people. Judith Snow's feature article in this issue puts a finger on labelling as a source or trigger of hatred and discrimination. Those labelling systems are instituted and authorised by the "helper" community of carers, treaters, and researchers and by the funding agencies. I hate to believe that labelling can cause us to kill, but I know that labelling discriminates, that discrimination devalues and objectifies, and I know too that things of lower value can be harmlessly disposed.

### Catastrophe of Compliance

I came across an article in the *Journal of Child and Youth Care* (1994, Vol 9, pp 13-21) by Lorraine E. Fox, called "The catastrophe of compliance". This is one of those articles which I hope is not needed anymore for the rehabilitation environment, but I am not sure. It is the story of how children and youth (able bodied but maltreated or abused or addicted or "system- kids"), who had been in a substitute care environment,

were given assertiveness training as part of their final, pre-release or pre-graduation life skill training. The observations of Lorraine Fox who taught these classes are very poignant - and I do hope inapplicable to any rehabilitation or independent living training environment.

Yet, I will stop and discuss this article and its implications for "helper" behaviour. Fox begins with a description of the first exercise which she asked the kids to do and which consists of two parts. In the first part the participants, having been divided into two groups, must ask their peers in the other group for something, material or a favour, reasonable or unreasonable. These requests must be expressed both verbally and in writing. In the second part of the

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### **"We preach empowerment, but we reward compliance."**

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exercise the participants were asked to refuse the requests from their peers in the other group, again in voice and writing. The exercise then, in bare bones, was: being able to ask for something and being able to say no to a request. Both the question and the refusal are made to peers, that is, persons of equal status, people with no higher power or superior position or role.

The participants had very serious difficulties both with the framing and posing of the question and with the refusal of requests made by others. Many justified their behaviour by saying "She told me I couldn't." One participant could not cope with the situation and had to be removed because she "started to deteriorate so badly." Fox, for whom these exercises were routine opening games for an assertiveness training session, was stunned and continues to elaborate

what she calls the "DILEMMA", which, "for our children and youth is that, in this compliance oriented society, they have been compliant!" And, for the abused children that Fox's article describes, this compliance with their tormentors, abusers, or drug-using peers has brought them "unspeakable pain".

I know that these youth are very different from the children and young people that we meet in rehabilitation environments - on the surface at least. I have often marvelled at the degree of compliance and the capacity for suffering that I have seen in children and young adults with disabilities. I have admired it and now I dread it. No-one can be that good. Is the extreme compliance present because the severely disabled child simply has no option? They cannot afford to lose the one or two people who are keeping them alive and so they do not have the option to ask for big or even small things. They may (perceive that they do) not have the option to say NO!! because they cannot afford to do so. Or, is it because they have never learned to ask, they have never been taught that they can say NO! (or "no but I still love you")? Or, have they never been allowed to say NO!

Compliance, as Fox says, "gets and keeps jobs, compliance gets diplomas and degrees; ... and compliance buys acceptance into families and situations that can drive you literally crazy." And she continues: "If children had the real ability to be non-compliant, they wouldn't get hurt!" Then she comes to the "CATASTROPHE", which is "that, in many cases, our practice doesn't match our rhetoric. We preach empowerment, but we reward compliance." And that sounds almost recognisable in any institution, any work or family environment. Fox uses the term "forced compliance" and it made me think of



“learned helplessness” and the two concepts look to be intimately related. I cannot help but wonder if it would not be easier to avoid learned helplessness if we get rid of the forced compliance models of care. The term compliance to me is still inextricably linked to the medical model, although its use of late seems to have abated.

A quotable quote is in order here; from Goffman (in Fox), who in 1961 said that “institutions (‘asylums’) were really organised around the needs of staff more than around the needs of residents.” Have we really changed? What has all our talk about empowerment and client centred service done to change our institutions? What are the physical changes that you can point out that show that the clients, the children, the parents are now more empowered? How can we tell when or that we are on the right track?

Here I take some final clues from Lorraine Fox. The question: “How successful are we in empowering our clients?” has an answer in our willingness to teach our clients to learn to be assertive and in our ability to allow them to be assertive. Fox compares this process to allowing a child to learn to play a new musical instrument. It (i.e. suffering the mastering of a musical instrument) is not a pleasant experience and neither is empowerment, at first. “Kids [and parents] practising assertion sound aggressive. Kids [and parents] learning to make choices often make difficult ones to live with. And it takes sooooo long for them to decide!” Empowerment is painful both on staff and on parents. But without this discomfort, this pain we are not going to change the compliant culture that we have created in our care institutions. And without true empowerment of our clients we will continue to graduate people who have been taught to be compliant but who have never learned to ask for the moon and to say NO when they should for their own best interest.

This compliance or compliant behaviour (or should one say complicity) remains present in many adults who are very dependent on medical support or attendant care. This combination of compliance and dependence creates an enormous vulnerability, a sense of impermanence and a weak self concept. Invariably this leads to behaviour that is too easily interpreted as helplessness or lack of competence.

### **The Moon; or a ‘Rational and Economical Basis for Care’ Model**

The last thing I wanted to talk about is a model of treatment, care, service and research, that is “logical and rational” — one that is driven by the consumers’ needs rather than by the needs of the persons who get paid for treating, caring, providing service, or carrying out research. A model that is driven by the people who want most to become, be and remain fit, or healthy and independent. Perhaps we should not even call it a model but rather consider the attitudes and expectations, that I will for the moment call ‘the model’, as an expression or integral part of the quality of life, the dignity and rights of all people.

Let me first make clear where I see a serious problem with our current health (&) care model. A person who gets paid for curing people who are ill or for caring for persons who are disabled is, however perverse this may sound, served by maintaining illness and disability, not by preventing or removing sources or causes of illness or by delabelling disabilities. Under the present system (of service provision and remuneration) professionals are not served by removing classifications or labels that sustain their job or profession. A person who lives on the avails of therapy must have clients who require therapy. A nurse can only survive when she is able to care for the sick. And as long as the providers, treaters, or carers set the goals and

make the prominent recommendations to health care and rehabilitation technology equipment funding authorities we will continue to create an illness or disability maintenance system not a prevention, wellness, or independence model.

So how does one go about reversing the priorities? What does one do so that the motivation of the patient / client is *the desire to be as independent as possible, irrespective of one’s level of ability?*

How can we make this become the driving and dominant motivation that impels all decisions and all actions in the new model?

My ideas about what a new model of (health) care should look like are influenced by my personal experiences and by two books. The books are Ivan Illich’s “Limits to Medicine” (Illich, 1976) and James Lovelock’s “The Ages of Gaia: A biography of our living earth” (Lovelock, 1988). I will defer broader discussion of these books to a future issue other than to say that Illich’s book has as its main thesis that the “medical industrial complex” in the Western world has literally outgrown its useful functions and now does more harm than good. We have become so dependent on medical services and categories that we have lost to a large extent our ability and freedom to heal ourselves.

Lovelock’s book elaborates on the concept of Gaia, the living creature which is earth and its immediate biosphere. Gaia’s health too is being threatened, by our habits, our insecurities, our greed and short-sightedness. Gaia has survived more species than we will ever know, and our environmental despoliations are likely to cause a change in earth’s environmental system which will make it un- or less fit for us, people, to survive.

Now what about that model? If labelling kills, compliance causes pain or suffering, and our society is so thoroughly “medicalized” that every



disease, every disability, every "deviation" (including, for example, infertility) is classified as a disease and has its own label, its own cost category, its own team of specialists, buildings, associations, journals, foundations, its own cure/treatment-regime, mystique and its own social and psychological stigmas, how can we build a saner model of well-being? If our self-serving habits are affecting Gaia itself, maybe a new model for rehabilitation care and service can contribute to the well-being of Gaia.

Well, you've got to start somewhere, and rehabilitation is a field populated with people who know pain, and who are no strangers to suffering and death. People who are able to accept pain and death as part of the coinage of living are, when given half a chance, better able to avoid, at least, the psychological dependency on medical services. The model that I have in mind is one that consists of practices of friends who, though medically extremely "fragile", have yet learned to retain a degree of freedom that many non-disabled persons lack.

The model that I propose consists of a list of best practices, a list which I will start in this issue but which I will hope to continue with

help from the readers, in future issues of **Communicating Together**.

## First Characteristics/Rules

### *I. Control your own health and independence.*

The person who has control over his or her health and independence is the person who checks his/her skin every night for red spots to avoid developing bed sores, the person who directs his/her attendant to prepare the food, select and administer the (prescribed) medication, the person who directs the therapist in choosing a chair, splint, brace, housing unit, respirator, and environmental control device.

What is needed for this level of control is:

- (1) knowledge of your own life and your condition and needs and the characteristics of the ailments or disablements that lurk
- (2) accepting the responsibility for your own well being / healing
- (3) the belief that you can actually control your own health and independence

What this first characteristic will give you: the ability to be in control of almost anything else in your life too —

your job, your volunteer work, your committee participation (chairing), the works.

### *II. Live with the lowest (rehabilitation and/or medical) technology possible.*

Examples of this rule are found in a person who learns to live without a rehabilitation technology device such as a ventilator (by learning how to frog breathe). Or any of us who can forestall the use of high tech intervention (e.g. open-heart surgery) by living healthier. What is needed are again the points above — knowledge, responsibility and daring. What you get out of following this rule is more control over your life and less chance of unwanted breakdown.

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# CONTENTS

<b>2</b>	<b>EDITORIAL</b> Integration, Inclusion, Quality of Care	NOLA MILLIN SHIRLEY McNAUGHTON PETER LINDSAY
<hr/>		
	<b>FEATURES</b>	
<b>4</b>	Responding to the Death of Tracy Latimer	JUDITH SNOW
<b>5</b>	Commentary on the Death of Tracy Latimer	VERNA THOMPSON
<hr/>		
	<b>YUCKS &amp; WOWS</b>	
<b>7</b>	Integration versus Segregation	ANGELA JOSLIN
<hr/>		
	<b>TEACHING AND LEARNING</b>	
<b>8</b>	Communicating with Signs, Sounds and Symbols	NOLA MILLIN
<b>9</b>	Training Horizons for Adults in Transition — T.H.A.T.	SUZANNE CLANCY
<hr/>		
<b>11</b>	<b>CONSUMING TECHNOLOGY</b> Mainstream Computers versus Dedicated Aids (2)	ROBERT HAAF
<hr/>		
<b>14</b>	<b>KARI'S SKALLAGRIGG — PART TWO</b>	KARI HARRINGTON
<hr/>		
	<b>PERSPECTIVE</b>	
<b>15</b>	Communicating Togetherness or To the Far Side?	MAX KORN
<b>18</b>	Till She's Free	SHIRLEY McNAUGHTON
<hr/>		
<b>19</b>	<b>ADAPTING</b> Quality of Care in a Chronic Care Hospital	BRIAN PAMPLIN
<hr/>		
<b>20</b>	<b>PAUL'S PLACE</b> Rising Above	PAUL MARSHALL
<hr/>		
<b>21</b>	<b>CONTEXTS</b> Labelling = Murders?	GEB VERBURG

**Communicating Together**, established in 1982, is published quarterly by *Sharing to Learn*. Its mandate is to provide a means of sharing the life experiences and communication systems of augmentative communicators with other augmentative communicators, their families, their communities and those who work with them.

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**Typesetting & Printing:** Central Printing Services, Guelph, Ontario

#### Subscription Rates per Year:

Canadian - \$25.00 Cdn;  
U.S. - \$23.00 U.S.;  
Outside North America - \$30.00 Cdn.

#### ISAAC Members' Rates

Canadian - \$20.00 Cdn  
U.S. - \$17.00 U.S.  
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**Cover:** The cover presents a portrait of Judith Snow, author of the first feature article.

The publisher offers **Communicating Together** as a vehicle for editors, associate editors and contributing authors to present their perspectives on augmentative and alternative communication. The views expressed are not necessarily those of the publisher although the human interest, consumer involvement and international perspective are.

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**Communicating Together** is an affiliated publication of the International Society for Augmentative and Alternative Communication.

Second Class Mail Registration No. 7093  
GST Registration No. R130220619  
ISSN No. 822-0638